

RESOURCE GUIDE FOR FAMILIES FACING CHILDHOOD CANCER

DEVELOPED BY
ONCOLOGY FAMILIES *for* FAMILIES



A quick reference guide for families whose children have been diagnosed with cancer and are being treated at SickKids.

WHAT YOU WILL FIND INSIDE:

- Financial assistance resources
- Practical services at the hospital
- Support programs and groups
- Recreational programs and camps
- Wish-granting organizations
- Information sources

This Resource Guide belongs to:

From our families to yours:

This booklet was developed by families of the SickKids Haematology/Oncology Family Advisory Council for other families. It contains practical tips from parents as well as helpful resources that can support families, especially during the early stages of coping with your child's diagnosis.

As families of children with cancer, we know this is a difficult time and we hope the information in this booklet will help your family more easily access the people, places, information and support available at SickKids and beyond in your communities.

We encourage you to customize it with your contacts and to keep it handy so you can refer to it when you're ready. Please use this booklet in conjunction with other available SickKids resources, including the Oncology Guidebook you received.

And if you would like to share your feedback or tips to be included in future revisions of this booklet, please visit www.sickkids.ca/familyfeedback.

*Warm regards,
SickKids Haematology/Oncology
Family Advisory Council*

Key people you'll meet in the days after diagnosis

Primary Oncologist/Staff Physician

Your Oncologist: _____

Number: _____

Email: _____

Contact Nurse

Your Contact Nurse: _____

Clinic main number: 416-813-5859

Voicemail number: 416-813-7654 ext. _____

Email: _____

Social Worker

Your Social Worker: _____

Number: _____

Email: _____

POGO Interlink Nurse:

Your POGO Interlink Nurse: _____

Number: _____

Email: _____

Parent Liaison:

Ontario Parents Advocating for Children with Cancer's (OPACC) Parent Liaison provides one-on-one support on Mon., Wed., Thurs. and Fri. mornings from 10:30 a.m. to 12 p.m. from a parent who has had a child with cancer at the Sears Cancer Clinic.

OPACC Parent Liaison: Susan Kuczynski and John Pasternak
Hospital voicemail: 416-543-3701
Email: liaison@opacc.org or liaison2@opacc.org

Here are some other health-care professionals that are available to you:

- Child Life Specialist
- Pharmacist
- Dietitian
- Psychiatrist
- Psychologist
- Physiotherapist
- Nurse Practitioner

Other important names and numbers to keep on hand:

Name/title: _____

Number: _____

Email: _____

Name/title: _____

Number: _____

Email: _____

Financial Resources and Programs

To find out more or to apply for any of the financial resources and programs, please speak to your POGO Interlink Nurse or Social Worker.

PARENT TIP

Your family may be eligible for some of the programs that can help with the costs of parking and meals.

We encourage you to speak with your health-care team about your family's specific financial needs.

PARENT TIP

Ask for a copy of Pediatric Oncology Group of Ontario's Money Matters booklet.

It explains eligibility requirements and how to apply for these programs. Families are encouraged to keep their receipts.

Parking

SickKids has a regular daily rate, but take advantage of the parent multi-use and long-stay passes. Find out about current parking rates and passes at www.sickkids.ca/VisitingSickKids/Getting-to-SickKids/Parking/index.html.

Accommodations

Visit www.sickkids.ca/VisitingSickKids/Staying-at-SickKids/Nearby-accommodations/index.html for information about accommodations nearby, including Ronald McDonald House.

Financial Assistance

POGO Financial Assistance Program (POFAP) www.pogo.ca

- The POGO Financial Assistance Program is available to help Ontario families with out-of-pocket expenses for food and accommodation, as well as child care for siblings under the age of 12, when a parent accompanies a child to hospital during active cancer treatment.

Assistance for outpatient drug costs



- Workplace Drug Plans
- Trillium Drug Program (TDP)

Government insurance programs

- Employment Insurance (EI) Sickness Benefits
- EI Compassionate Care Benefits
- EI Parents of Critically Ill Children (PCIC)

Private insurance programs

- Short-term Disability Benefits
- Long-term Disability Benefits

Other programs

- Assistance for Children with Severe Disabilities (ACSD)
- Disability Tax Credit (DTC)
- Medical Expenses Tax Credit
- Northern Health Travel Grant (For Northern Ontario residents who must travel at least 100 kilometres one way)

Rides to treatment

- Canadian Cancer Society's
Wheels of Hope Transportation Service
1-888-939-3333
www.cancer.ca/wheelsofhope
transportation@ontario.cancer.ca
- The Wheels of Hope Transportation Service in Ontario may be able to offer some subsidies and rides to cancer-related treatment.



Canadian Cancer Society
Société canadienne du cancer

SickKids Practical Services

PARENT TIP

You can pick up takeout to bring back to the hospital room OR have it delivered and meet the driver in the Elizabeth Street entrance lobby.

Many websites allow you to search online by using the SickKids address: 555 University Ave., Toronto, ON

SERVICE

HOW TO GET IT

SickKids' FREE wireless network (WiFi)

Connect to the SickKidsGuest network. The password is beourguest. Ask for the Welcome to SickKids WiFi info sheet available in your nursing station.

Parent meals delivered to your child's room

Call the hospital's Meal Train office at ext. 206622 for a guest tray menu. Make your menu choices and pre-pay at the Main Floor Terrace Café.

SickKids late night restaurant is The Fountain

Open 7 p.m. to midnight in the Main Floor Atrium Wing between Subway and the Terrace Café entrance.

Parent fridges and microwaves on 8A and 6E

Store your nut-free food in the fridge and it can be heated in microwaves available on inpatient units.

FREE 24-hour laundry facilities (OPACC provides free detergent for use by parents)

4th floor, Room 4308.

Child and Family Relations Service

Room M223, Black Wing, Main Floor

Tel: 416-813-6181

email: cfr.experience@sickkids.ca

Interpreter Services at SickKids If you have limited English proficiency or are deaf or hard of hearing.

Speak to your health-care team or advise Child and Family Relations (see item above for contact info)

School at SickKids for inpatients

There is no minimum stay for patients to be enrolled in the SickKids school program. Speak to your POGO Interlink Nurse or Social Worker to register.

Parent Tips - Clinic Visits

Chances are that if you aren't staying in the hospital, you will be coming to the Sears Cancer Clinic (Haematology/Oncology Clinic) on the 8th Floor for your child's doctor appointments and treatment. To help you find your way around the clinic, see the clinic map on the back cover of this booklet. The clinic is a busy place, so here are some tips to keep in mind before you come:

- **Arrive 30 minutes** prior to your first appointment to register and remember to bring your child's OHIP health card and hospital card.
- **Come prepared** to spend a few hours on the day of your appointment—depending on what's scheduled. You'll be happy to know that Camp Oochigeas is on-site daily with activities for your child. You'll also find computers, games and a play kitchen.
- **Remember** to bring food and snacks with you. You may also want to bring along a family member or friend to help you and keep you company.
- **Listen carefully** for your child's name over the clinic's PA (announcement) system about where you need to go, such as a POD area, an exam room or the IV Room.
- **Record these** important phone numbers:

Clinic phone number: 416-813-5859

Staffed 8 a.m. – 4 p.m., Monday to Friday

After hours on-call doctor for medical emergencies:
416-813-7500

The doctor will be paged and will return your phone call.

PARENT TIP

Plan to arrive early.

PARENT TIP

Prepare for the day.

PARENT TIP

Bring food and snacks.

PARENT TIP

Listen for your child's name.

PARENT TIP

If you come to the Emergency Department, oncology patients are seen and triaged quickly.

- **Take the underground tunnel to walk to Princess Margaret Hospital (PMH)** if your child has an appointment/treatment there. Go to the SickKids Black Wing elevators on the Main Floor and press the elevator button labeled 'PMH Tunnel'. When you exit the elevator, follow the signs. It may be a bit difficult to navigate the first time. If your child is having treatment at PMH, you may wish to park at SickKids.

Care closer to home

In addition to the Sears Cancer Clinic at SickKids, some of your child's treatment and supportive care may be provided closer to your home through POGO's Provincial Pediatric Oncology Satellite Program. Ask your health-care team.

POGO SATELLITE CLINIC	LOCATION
Trillium Health Partners, Credit Valley Hospital	Mississauga
Grand River Hospital	Kitchener-Waterloo
Orillia Soldiers' Memorial Hospital	Orillia
Northeast Cancer Centre, Health Sciences North	Sudbury
Windsor Regional Hospital	Windsor
Rouge Valley Centenary	Scarborough
Southlake Regional Health Centre	Newmarket

Support Services offered at SickKids:

SERVICE	HOW TO GET IT
AboutKidsHealth website <ul style="list-style-type: none"> Trusted answers from SickKids about prescription drugs and illnesses Information is available in English and other languages 	www.aboutkidshealth.ca
Bear Theatre's Tails musical production <ul style="list-style-type: none"> FREE performance every Thursday night at 6 p.m. SickKids staff and volunteers, helps ease the anxiety of hospitalization and treatment 	Thursdays at 6 p.m. on the 4th Floor
Camp Oochigeas Ooch In-Hospital Program <ul style="list-style-type: none"> Provides fun and interactive programs for children ages 0-18 Delivers camp-style programs seven days a week and four evenings a week to children on the Oncology/ Haematology floors 	See the Camp Ooch In-Hospital Program schedule on page 11
The Play Park <ul style="list-style-type: none"> The Play Park is a project of the Women's Auxiliary in partnership with the Canadian Tire Foundation for Families and is for brothers and sisters of patients who are staying in the hospital or visiting clinic Children under age 2½ must be accompanied by an adult 	Main Floor, Atrium Hours: Monday to Friday 8:30 a.m. - 4 p.m. Saturday and Sunday 11:30 a.m. - 3:15 p.m.
Yoga Wellness Program (Gilda's Club Greater Toronto) <ul style="list-style-type: none"> Free yoga for parents/caregivers (mats provided) 	Room 8704 For more information regarding the current yoga schedule, please contact: Ali Henderson, Program Director ali.henderson@gildasclubtoronto.org

PARENT TIP

For support specific to your family's needs, please speak to your Social Worker or POGO Interlink Nurse.

Support Services offered at SickKids cont'd:

SERVICE	HOW TO GET IT
Marnie's Place <ul style="list-style-type: none">· A comfortable room for patients to play computer games, watch TV, play pool or board games	4th Floor, Room 4318
Parent Liaison (OPACC) <ul style="list-style-type: none">· Community resources, information, support and family events	Mon. 10:30 a.m. - 12:30 p.m. (Sears Cancer Clinic, room 8102) Wed., Thurs., Fri. 10:30 a.m. - noon (Sears Cancer Clinic, kitchen area near the IV room)
Playrooms on most inpatient units	If your child cannot leave their room, ask for Child Life.
Starlight Room <ul style="list-style-type: none">· Video games, crafts and movies· Room is open to ALL patients AND siblings hospital-wide· Staffed by a Child Life Specialist· It is important to check with a nurse to ensure your child can leave the unit to go to Starlight Room	9th Floor Atrium

Camp Ooch Out-Patient Program Schedule (Clinic/8D)

	MORNING (9 a.m. - noon)	AFTERNOON (2 - 3:30 p.m.)
MONDAY	Clinic	8D Playroom
TUESDAY	Clinic	8D Playroom
WEDNESDAY	Clinic	No Playroom
THURSDAY	Clinic	8D Playroom
FRIDAY	Clinic	8D Playroom

PARENT TIP

Look for the Ooch staff member wearing a coloured braid.

Camp Ooch In-Patient Program Schedule (8A/6E)

Note: patients on 6E will receive bedside visits and are welcome to the 8A Playroom for Ooch programs.

	MORNING	AFTERNOON (2 - 3:30 p.m.)	EVENING (6 - 8:30 p.m.)
SUNDAY	Bedside visits	Rm 8704 (1 - 3 p.m.)	No Program
MONDAY	Bedside visits	8A Playroom	8A Playroom (Sept - June)
TUESDAY	Parent and Tot Program in 8A Playroom (11 a.m. - noon)	8A Playroom	8A Playroom (Sept - June)
WEDNESDAY	Bedside visits	No Program	8A Playroom
THURSDAY	Parent and Tot Program in 8A Playroom (11 a.m. - noon)	8A Playroom	8A Playroom (Sept - June)
FRIDAY	Bedside visits	8A Playroom	No Program
SATURDAY	Bedside visits	Rm 8704 (1 - 3 p.m.)	No Program

PARENT TIP

If your child is in 8B, Camp Ooch is available all day to do bedside programming.




PARENT TIP


Families often connect through Facebook and other online groups that are organized and monitored by parents. Ask other families you meet if they are part of any such groups. Often, you must ask to be 'approved' by another parent member to participate.

Support Services beyond SickKids and online:




SERVICE	HOW TO GET IT
Camp Quality's Puppet Show <ul style="list-style-type: none">Elementary school performances encourage sensitivity about cancer and its effects	www.campquality.org
Carepages <ul style="list-style-type: none">Private, personalized web pages to automatically update your network	www.carepages.com/sickkids
CaringBridge <ul style="list-style-type: none">Share news and receive support online<i>SupportPlanner</i> allows your network to organize care and tasks for you	www.caringbridge.org
Pediatric Oncology Group of Ontario (POGO) offers: <ul style="list-style-type: none">An online Childhood Cancer Resource Guide of community, provincial and government servicesPsychosocial resourcesInformation on exercise, nutrition and well-being, included in the Healthy Lifestyles BookletFinancial Assistance Program to help with out-of-pocket expenses (see POFAP on page 4)And more supports while your child is in treatment and beyond	For details, contact your POGO Interlink Nurse or Social Worker, and visit www.pogo.ca
YMCA FREE passes <ul style="list-style-type: none">Recreation facility at 20 Grosvenor Street, Toronto	Available through the SickKids Family Centre

Parent and Family Support Groups - Local Communities

LOCATION	PROGRAM
SickKids, Toronto	<p>Parent Support Groups hosted by Ontario Parents Advocating for Children with Cancer (OPACC) staff and volunteers</p> <p>Weekly coffee hours and support group meetings.</p> <p>Monday morning coffee hour, Sears Cancer Clinic (Room 8102), 10:30 a.m. - 12:30 p.m.</p> <p>Parent support group every Tuesday evening at SickKids, 6:30 p.m. - 8:30 p.m., 8th floor board room (Room 8704)</p> <p>Parent Liaisons are also available for informal visits on the inpatient units.</p> <p>For more information: 416-543-3701 liaison@opacc.org www.opacc.org</p> 
Toronto	<p>Gilda's Club offers free psycho-social and emotional support to children, teens and adults touched by cancer. Programming includes children/teen support groups & bereavement, parent bereavement, healthy lifestyles, digital storytelling, camp, and more.</p> <p>Gilda's Club, 416-214-9898 www.gildasclubtoronto.org</p> 
Toronto Halton/Peel Brampton Niagara London	<p>Wellspring Cancer Support Network offers psychosocial, emotional, restorative, practical and educational support programs for children and parents, teens, young adults and their family/caregivers, free of charge.</p> <p>Birmingham Gilgan House (Oakville): 905-257-1988 Downtown Toronto: 416-961-1928 Westerkirk House at Sunnybrook: 416-480-4440 Chinguacousy (Brampton): 905-792-6480 Wellspring Niagara: 905-684-7619 Wellspring London: 519-438-7379 www.wellspring.ca</p> 

LOCATION	PROGRAM
Durham Region (Oshawa)	<p>Hearth Place Cancer Support Centre offers monthly family support groups, sibling and teen support, fun days and individual play, art and music therapy for children with cancer. Practical assistance, peer support and grief counseling also provided. Programs are available free of charge.</p> <p>Contact Carolyn at Hearth Place Cancer Support Centre: 905-579-4833 or email Carolyn@hearthplace.org</p> <p>www.hearthplace.org</p> 
Barrie	<p>Candlelighters Simcoe</p> <p>Parents of children with cancer meet the first Monday of the month September to June.</p> <p>Contact Barbara Johnson, Parent Liaison 705-737-4296 or email barb@candlelighterssimcoe.ca</p> <p>www.candlelighterssimcoe.ca</p> 
Barrie	<p>Gilda's Club Simcoe Muskoka, Barrie</p> <p>Free psycho-social and emotional support to children, teens and adults touched by cancer. Programming includes children/teen and family support groups, healthy lifestyles, seminars, workshops, and more.</p> <p>705-726-5199</p> <p>www.gildasclubsimcoemuskoka.org</p> 
Newmarket/ York Region	<p>Drop-in, community-based parent group for families of children with cancer.</p> <p>3rd Monday of every month, 7 - 8:30 p.m.</p> <p>56 Forhan Ave. (Optimist Club Newmarket)</p> <p>RSVP to Nicole at 647-389-2306 or John at 416-953-6025 or Newmarket.opacc@gmail.com</p> <p>www.opacc.org</p> 

Parent and Family Support Groups - Local Communities *cont'd*

LOCATION	PROGRAM
Hamilton	<p>Drop-in, community-based parent group for families of children with cancer meets the 2nd Tuesday of every month, 7 - 8:30 p.m.</p> <p>1510 Main St. West (Ronald McDonald House, Hamilton)</p> <p>RSVP to Hamilton.opacc@gmail.com or call Carrie at 519-802-7885 or Corinne at 289-700-4697</p> 
Kitchener-Waterloo	<p>Drop-in, community-based parent group for families of children with cancer meets 2nd Tuesday of every month, 7 - 8:30 p.m.</p> <p>16 Andrew St. #2, (HopeSpring Cancer Support Centre, Kitchener)</p> <p>RSVP to Lisa at 519-208-8647 or Helen at 519-885-6527</p> <p>www.opacc.org</p> 
Ottawa	<p>Candlelighters Childhood Cancer Support Programs</p> <p>613-715-9157</p> <p>www.candlelighters.net</p> 

* Programs current as of date of publishing. Contact the organization to get most updated group dates/times.

Recreational Programs, Camps and Wish-Granting Organizations

The opportunity to connect your child with other children facing a similar experience or the chance for the entire family to ‘get away from it all’ and just have fun may be just what the doctor ordered!

Recreational programs and events

- Million Dollar Smiles’ Holiday Bear Drive with Toys “R” Us gift card and playground sponsorship

For more information please visit
www.milliondollarsmiles.ca
or call Anna Lopes at 416-566-0554
(email: info@milliondollarsmiles.ca)



- Starlight Children’s Foundation Canada offers a variety of family-based programs and activities including picnics, movie screenings, sporting events and more.

www.starlightcanada.org
or call 1-800-880-1004



Children and family camps

- Camp Oochigeas offers Residential Camp programs in Muskoka, Camper and family In-City programs.

For more information
please visit www.ooch.org
or contact us at, 416-961-6624
or registration@ooch.org



- Camp Quality offers week-long camp programs for patients and siblings. Family programs also available. Camp is open to patients with Cancer as well as those with Marrow Failure.

www.campquality.org
1-866-738-8011
or info@campquality.org



- Camp Trillium offers a variety of residential camp programs year-round for patients, siblings and parents across the province.

www.camptrillium.com
or call 1-888-999-2267
or info@camptrillium.com



- Gilda's Club, Greater Toronto, offers In-City Camps

For more information please visit
www.gildasclubtoronto.org
for March Break and Summer camps



Wish-granting organizations

These organizations grant wishes for children with serious illnesses. See their websites for eligibility and how to apply.



Children's Wish Foundation of Canada
www.childrenswish.ca or call 1-800-267-WISH(9474).



Make-A-Wish® Canada
www.makeawish.ca or call 1-888-822-9474.



Starlight Children's Foundation Canada
www.starlightcanada.org or call 1-800-880-1004.

PARENT TIP

You can only register with one Wish organization. Check with the individual organizations about registering in advance and timelines for your child's wish.

Other sources of information

Here are just some of the organizations that offer childhood cancer information.

CHILDHOOD CANCER AND CANCER INFORMATION ORGANIZATIONS

Canadian Cancer Society	www.cancer.ca
Cancer Care Ontario	www.cancercare.on.ca
Childhood Cancer Canada	www.childhoodcancer.ca
CureSearch	www.curesearch.org
Health Canada	www.hc-sc.gc.ca
Leukemia Lymphoma Society	www.llscanada.org
National Cancer Institute (US)	www.cancer.gov
Ontario Parents Advocating for Children with Cancer (OPACC)	www.opacc.org
Pediatric Oncology Group of Ontario (POGO)	www.pogo.ca
SickKids AboutKidsHealth	www.aboutkidshealth.ca

PARENT TIP

For more general information about navigating through your SickKids experience, visit www.sickkids.ca/VisitingSickKids/index.html or refer to the Oncology Binder Handbook you were given.

This Resource Guide for Families Facing Childhood Cancer was developed by the SickKids Haematology/Oncology Family Advisory Council (FAC), comprised of families and SickKids staff. This resource book will be revised annually.

Help us support newly diagnosed families by providing your compliments, comments and ideas for future editions of this resource book at www.sickkids.ca/familyfeedback

Sources: POGO's Money Matters Booklet, SickKids' Family Guidebook, Oncology binder/handbook, organization websites

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What else I want to check on for my family
or questions to ask my team

1. _____

2. _____

3. _____

4. _____

5. _____

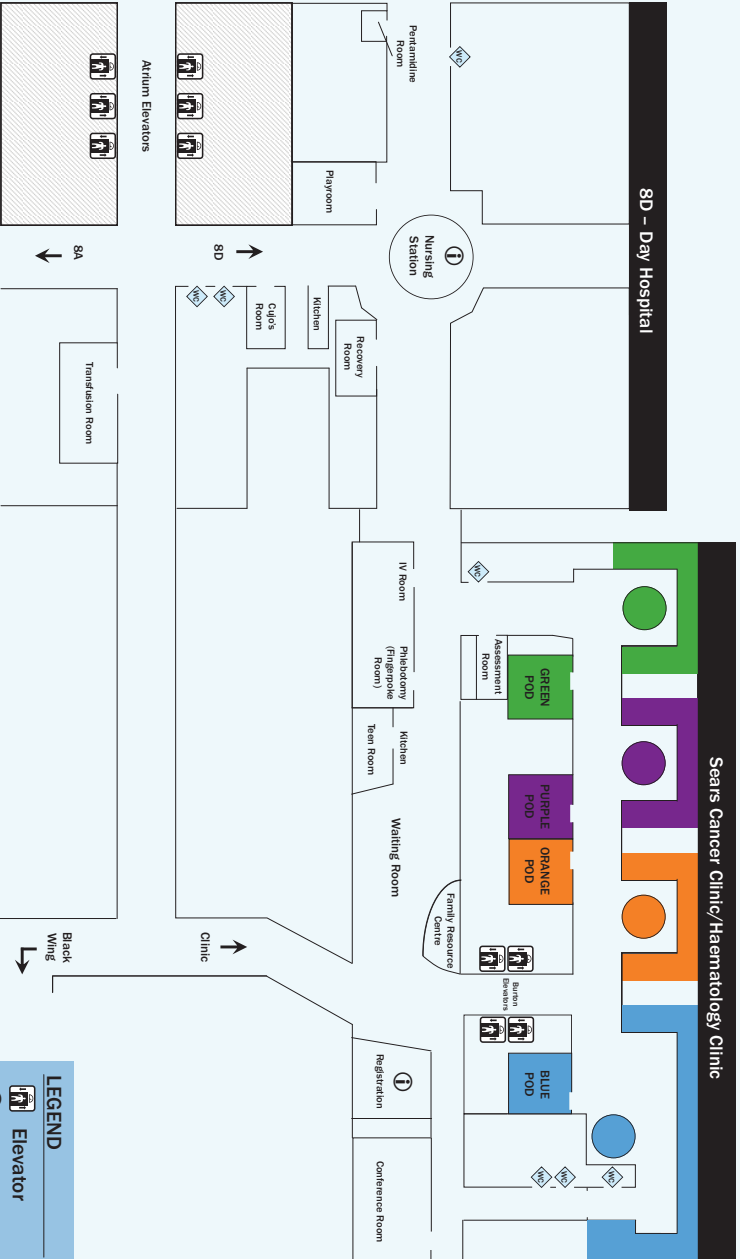
6. _____

7. _____

8. _____

9. _____

10. _____



LEGEND

-  Elevator
-  Information
-  Washroom

Map is not to scale. Last updated on June 4, 2014.

Map developed by Aifred Lam
(3rd Year Ryerson Nursing Student)